Elements of successful integrated personalised care

A model and guide to transform cancer care and support in England

MACMILLAN CANCER SUPPORT

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Contents

Summary

Macmillan Cancer Support has been working alongside people living with cancer and our partners in communities and health services for many years to develop models of care that improve the quality of life for people living with cancer through personalised care and support.

This is a short, practical guide to Macmillan's model of Integrated Personalised Care and the key considerations and enablers for partners to implement a successful system-wide intervention to transform the experience of people living with cancer.

This builds on our **'Making the case'** report, which outlined why we need a new approach to supporting people living with cancer. This is intended to be the start of a conversation between partners and Macmillan's local partnership teams. At the end of the guide, you will find further resources on how to take this forward in your system.

Please get in touch if you would like any further information: **personalisedcare@macmillan.org.uk.**

Elements of successful integrated personalised cancer care

1

Everyone with cancer should be able to access a dedicated Link Worker
Through the use of a Holistic Needs Assessment (HNA) a Link Worker should identify a person's needs and generate a tailored care and support plan that ackowledges the person's own resources and capabilities.

2

Support must be systematically and proactively offered to everyone diagnosed with cancer
Access to support must be opt-out and systematically offered to everyone from the point of diagnosis to ensure those who need support can find it.

3

Every concern raised should have a route into appropriate support
Experiences won't improve if needs are identified and not addressed. Any intervention must ensure that wherever possible there is a route into an appropriate form of support, including referral back into acute or primary care for clinical concerns.

4

Holistic support must be provided within and beyond hospital settings
No one setting can nor should provide all the support a person with cancer needs. Extending beyond hospital settings will allow greater focus on non-clinical needs alongside clinical concerns.

5

Services must be co-produced with people affected by cancer
Engagement with individuals, groups and organisations should be built into service development from the start. Co-produced and authentic involvement creates more sustainable and impactful solutions.

6

Work within the local context and build on local assets
Rather than develop a brand-new service, partners must work together to understand what is already there, how it knits together and how people feel about it, before going on to design an integrated response.

Enablers

- Leadership Buy-in
- Data-sharing and reporting across boundaries
- Stakeholder Engagement
- Robust Processes

Macmillan's model of Integrated Personalised Care

'Personalised care' is a broad term encompassing all the ways in which holistic needs are met. A personalised care approach should be in place from the point of diagnosis and throughout a person's cancer experience, intervening at the earliest possible opportunity as issues arise or are identified. This should not be a one-off conversation because needs change over time, so frequent check-ins are needed to ensure concerns can be identified and addressed.

The NHS Long Term Plan (2019) outlined how systems should enable patients to get support on what matters to them and contained a commitment that, where appropriate, **"every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.[1]"** Despite these national commitments, there is significant variation in who is accessing personalised care and the quality of the conversation, the support plan and the follow up they receive. Macmillan's model of integrated personalised care will allow systems to deliver on the duty to provide personalised cancer care and it will ensure greater reach to those who are not currently accessing support.

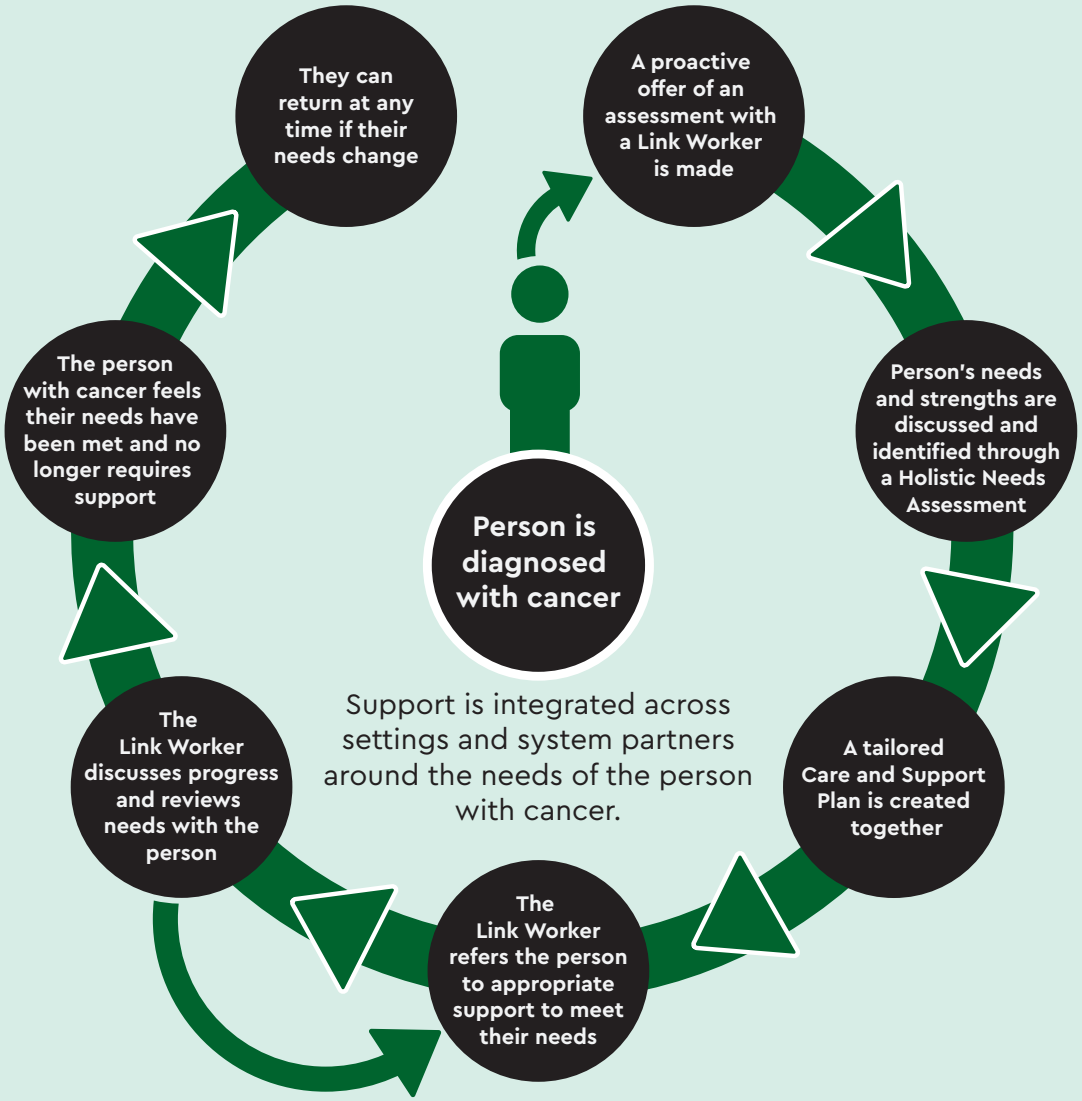
Ensuring personalised care is integrated across sectors and settings

Personalised Care and Support Planning must take place if people with cancer are to have their broader health and wellbeing needs met. Macmillan believes Holistic Needs Assessments (HNAs) and Personalised Care and Support Plans are the tools that can drive better personalised care and support. Truly integrated personalised care takes this one step further. By using these tools within a system-wide framework that is **proactive, universal** and **accessible** in a range of places, we can ensure a **tailored support** response that draws upon **cross-sector expertise** and is rooted within the context of **local communities**.

Integrated personalised care should be delivered across the system – in acute, primary and community settings – so it's accessible to all. It is about partners collaborating and joining up services to ensure people get access to the right care, at the right time, in the right place to meet their needs.

From Macmillan's experience in developing Improving the Cancer Journey, successful outcomes require personalised care to be considered as a whole-system integrated approach. People must be empowered to tap in and use their own resources more effectively, while harnessing contributions from partners providing support in their local community. This will help solve problems people are struggling with more effectively and sustainably.

Macmillan's Model of Integrated Personalised Care



"ICJ is a working example of the type of service aspired to by policy makers worldwide – holistic, person-centred, needs-driven, and delivered through collaboration."

Independent Evaluation of ICJ Glasgow

Improving the Cancer Journey – a pioneering model of integrated, personalised care[2]

Improving the Cancer Journey (ICJ) is an innovative, proactive service model that has successfully demonstrated the impact of Personalised Care and Support Planning and early holistic intervention. It is now being rolled out across all 31 Health and Social Care Partnerships in Scotland alongside local partners and the Scottish Government as part of the Transforming Cancer Care Partnership. Across Scotland each ICJ model is being designed and built by local system partners to effectively meet local needs and optimise the effectiveness of local resources.

Multi-disciplinary

ICJ Glasgow is a multi-agency approach, delivering a seamless service and unprecedented collaboration across health, social care and the third sector to improve the outcomes of people affected by cancer. First launched in 2014 by Glasgow City Council and now run by Glasgow City Health & Social Care Partnership, with Macmillan its main partner, it was unique in its proactive, multi-disciplinary and non-clinical approach. For example, by embedding housing support within the service team they were more successfully able to deal with one of the most frequently raised concerns of people living with cancer.

Proactive and multiple access points

Through co-operation with Public Health Scotland, everyone in the Glasgow city area with a confirmed cancer diagnosis received a letter of invitation for ICJ support. As ICJ Glasgow has grown and embedded, there are now multiple touchpoints that encourage a service user into the service including pre-diagnosis/suspected cancer pathways, rapid diagnostic centres, primary care, Clinical Nurse Specialists, multi-disciplinary teams, welfare benefits advisers, third sector partners, Macmillan community information and support services, as well as self-referral.

Needs assessment and care plan with a Link Worker

The ICJ intervention centred on the Holistic Needs Assessment (HNA), delivered by a dedicated Link Worker. Alongside the person with cancer, the Link Worker built a care plan and played a key role in supporting the person to access support from other services in their community, rather than just signposting on. By being based in the community, link workers had greater awareness of the range of support available within the community, which frontline health professionals may not have been able to build up.

Demonstrated reach into underserved communities

This integrated and non-clinical led approach has been proven to successfully reach those most in need of support. 76% of those accessing the service were from areas with the highest levels of deprivation in Glasgow. 20% of those the service supported were receiving palliative care and would not typically have received non-clinical support.

How to develop the conditions for Integrated Personalised Care in your system

Thanks to decades of experience supporting people living with cancer and working alongside our partners in communities and in local health and social care systems, we have a clear view of how to embed truly holistic care and support to improve the experiences of people affected by cancer. While we recognise the need for locally-driven approaches to delivering integrated, personalised and place-based cancer care and support, we have identified key conditions vital for success.

Core elements of a successful personalised cancer care model

1. Everyone with cancer should be able to access a dedicated Link Worker

While some people living with cancer do receive excellent access to Holistic Needs Assessments (HNAs) and Care and Support Plans from dedicated Care Coordinators, Clinical Nurse Specialists, Link Workers and Information and Support Workers, many more do not. For the most part, HNAs take place in clinical settings and do not work in a truly integrated way across services and other local assets.

Ensuring everyone with cancer can access a dedicated Link Worker, or equivalent, who will be responsible for facilitating an initial patient-led HNA is key. When it comes to HNAs, people with cancer may value the professional's ability to listen over a clinical qualification.

The advantage of having a link or support worker trained to provide non-clinical holistic support, is their extensive knowledge of local community assets. This could include, for example, support with transport to and from hospital appointments, childcare, housing concerns, exercise classes, wellbeing offers, support for pets, support for carers, accessing insurance and providing respite support. Alongside the person with cancer, the Link Worker builds a care plan and plays a key role in supporting the person into other services and navigating them through the system.

"Following my diagnosis, Macmillan cancer support workers... have provided me with a really positive experience. They supported me and my family by listening to our individual circumstances, providing helpful information and support, offering advice and signposting me to the appropriate place to help with my emotional and physical health following my diagnosis."

Elaine from Bristol,
diagnosed with breast cancer in 2016.

2. Support must be systematically and proactively offered to everyone diagnosed with cancer

By proactively offering everyone diagnosed with cancer access to an assessment of their broad health and wellbeing needs, we can ensure concerns are identified early and that appropriate, tailored support can be put in place to meet those needs. A systematic approach, proactively offered to everyone with a diagnosis living in a geographical footprint, ensures the element of chance is removed and instead access to support is universally offered. By implementing an 'opt-out' rather than an 'opt-in' approach, a service is much more likely to reach those who do not typically interact with support services and who may benefit much more from this intervention.

Example: In Glasgow, under the ICJ Service, a data-sharing agreement with partners used data from the Scottish Cancer Registry to ensure that everyone diagnosed with cancer in Glasgow received a letter within 8 weeks of diagnosis offering them an appointment with a social care-based link worker who completed a Holistic Needs Assessment with them to identify all their concerns and needs.[2]

Integrated Personalised Care – supporting patients' holistic needs

3. Every concern raised should have a route into appropriate support

Integrated personalised care and support will not work if a person's needs are identified but not addressed. Any intervention that is seeking to provide real holistic support for people living with cancer must ensure that wherever possible there is a route into an appropriate form of support. Integrated system partners should work together to understand what is available to people living with cancer in their local areas, to ensure gaps are understood and can be addressed.

4. Holistic support must be provided within and beyond hospital settings

Currently, how we offer cancer care and support is mostly organised around hospitals, not always around the needs of the individual or their family. An integrated, personalised, place-based service recognises that for the holistic needs of people living with cancer to be addressed, clinical and non-clinical teams must work together.

We know that integrated care often breaks down during transitions between services and needs can be overlooked – for example around follow-up care after discharge and mental health support. Clinical Nurse Specialists or other staff working in the acute setting may be aware of community services that can offer support. However, the main part of their role, and their expertise is to address a patient's clinical needs. Access to non-clinical support services, for example, social care, financial or housing support, can and should sit in a variety of different places. Link workers can sit in community spaces, GP surgeries, alongside clinicians within hospitals, Local Authority offices, or even over the phone. The choice of where to access support will allow the service to reach more people, particularly those who struggle or do not wish to access hospital spaces.

Example: The Evaluation of the ICJ Glasgow[2] service found only 10% of issues raised during HNAs and care planning discussions with Link Workers were clinical. The other 90% of concerns raised were non-clinical and could be better addressed by non-clinical staff with knowledge of and access to a diverse range of non-clinical support.

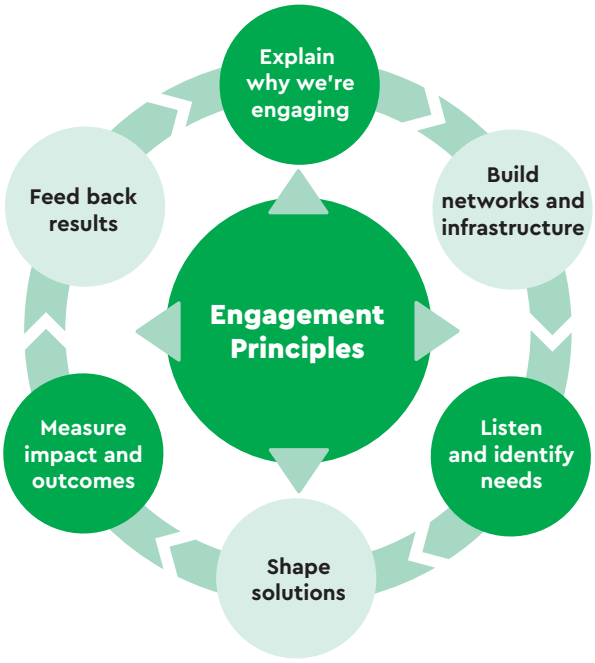
5. Services must be co-produced with people affected by cancer

Macmillan knows from experience that co-designed and authentic involvement in service development right from the start and throughout the process, creates more sustainable, impactful and person-led solutions. Working with people living with cancer to shape solutions enables systems to ensure that people can have access to personalised care that meets their varied and individual needs.

Co-production means engaging with people living with cancer throughout the process – from scoping, understanding and defining the problem through to testing and implementing a solution.

Ongoing conversations with individuals, groups and organisations around cancer care and support help to deepen understanding of what is working well and where the gaps are and should be built into service development from the beginning.

Example: Macmillan Joining the Dots (JTD) is an on-going partnership between Macmillan and Durham County Council, which seeks to improve the experiences of those affected by cancer in County Durham. JTD was developed with the direction of a co-production steering group who worked together as equal partners with system stakeholders. They co-designed new ways of working to make sure people affected by cancer had easy, consistent and clear access to support around their holistic needs. The group ensured people affected by cancer were involved in the design and optimisation of services and could provide knowledge as experts through experience.



6. Work within the local context and build on local assets

Developing a universal and fully integrated service must start with the local context and be designed with an understanding of the community's assets for it to be truly effective and to avoid duplication. Places will often already have services and systems to support many of the broader needs of people living with cancer – they are often just not connected or widely known about. The role of a Link Worker is to unlock the support available across the different layers in a system (see diagram page 16).

A truly diverse range of partners must work together, alongside people living with cancer, to understand the existing local support offer and how comfortable people from all communities feel in navigating it. Often support will be provided by the Voluntary, Community and Social Enterprise (VCSE) Sector and it is vital that VCSE partners are involved in developing any system intervention so that they can be part of identifying gaps in provision and co-designing solutions.

Rather than impose a brand-new service, a model of support should knit together the existing local community assets and fit around existing delivery structures. The development of Integrated Care Systems (ICSs) across England offers an important opportunity to embed integrated ways of working across health, social care, and the voluntary and community sector at system, place and neighbourhood level. This is significant because it allows health and care systems to be much more responsive to their local communities, developing and delivering models of care and support at the right scale and in the right place that will be most effective for their residents.

System-wide support that a Link Worker can help to unlock[3]

Enablers for success

Alongside the core elements of successful integrated personalised care, there are four enablers which will assist in turning this from an ambition to a reality:

1. Senior leadership buy-in

Partners and stakeholders providing care must be aligned and work together. To break down barriers between organisations and sectors to allow collaborative and effective working, senior buy-in and strong leadership is vital. This will ensure processes of collective working between partners within each organisation are put in place that can support the development of integrated personalised care. Leaders must buy-in to the vision, mission and partnership and work as advocates within their systems to drive a programme forward.

2. Data sharing and reporting across boundaries

A coordinated approach is needed to both collecting and sharing data to drive better quality decisions and service improvements, as well as ensure sustainability. Coordination of data collection, particularly on demographics, can also ensure support is targeted to those who need it. Data-sharing agreements concerning patients or service users and reporting across boundaries can overcome key barriers to integrated working. For example, currently performance monitoring of NHS personalised care targets focuses on acute settings which can act as a barrier to designing out of hospital services which may be better placed to deliver the right support for people living with cancer. By sharing data across settings through the use of electronic HNAs, targets can still be reported in acute settings, but completion could take place in the most relevant location for the person with cancer.

3. Stakeholder Engagement

Trust in a new approach will only be built through collaborative working and open and transparent communication between stakeholders. When stakeholders are engaged from the start, and kept informed throughout the process, the resulting service development is often much faster to develop and much more likely to be sustainable. Stakeholder engagement should involve all partners and particularly those organisations who have demonstrated reach into the most marginalised and underserved groups.

4. Robust Processes

Having clear and robust processes in place around governance, project management, co-production, monitoring, reporting and stakeholder engagement will enable the whole system to be responsible and accountable for their contributions and together learn and develop into the future. Improved understanding of referral pathways across the system will ensure more effective implementation and better outcomes and experiences for all people with cancer.

Further Resources

Macmillan has already started working with partners in systems across England to begin to deliver integrated personalised care in communities. Please get in touch with our local partnerships team via **personalisedcare@macmillan.org.uk** for further resources and to discuss how we can work together to transform the experiences of people living with cancer in your area.

References

1 The NHS Long Term Plan, 2019.
2 Evaluation of the Improving the Cancer Journey programme, Macmillan and Edinburgh Napier University, 2020.
3 Based on a diagram taken from NHS England and NHS Improvement's Community Mental Health Framework for Adults and Older Adults

At Macmillan, we give people with cancer everything we've got.
If you're diagnosed, your worries are our worries.
We will move mountains to help you live life as fully as you can.

And we don't stop there. We're going all out to find ever better ways to help people with cancer, helping to bring forward the day when everyone gets life-transforming support from day one.
We're doing whatever it takes. But without your help we can't support everyone who needs us.
To donate, volunteer, raise money or campaign with us, call **0300 1000 200** or visit **macmillan.org.uk**

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